

# Nutrition Care Pathway for People Living With Motor Neurone Disease in Dorset

All patients with an MND diagnosis should have access to a Registered Dietitian for nutritional assessment (MUST - Malnutrition Universal Screening Tool) and dietary advice particularly if 5%+ weight loss is identified. Conversations about artificial feeding should take place as early after diagnosis as is appropriate to the patient's psychological state involving the MND/MDT

**Dysphagia/weight loss**

Consultant (Neurologist/Palliative) to refer to SALT and Dietitian if not already involved

All members of the MND/MDT should be involved with decision making. Conversations with patient/spouse, next of kin, carer about what is involved in feeding tube insertion and artificial feeding, including explanation that oral diet can continue and that artificial feeding may become inappropriate at some point. Resources: 7B tube feeding & Information sheet No: 11 & [www.mytube.mymnd.org.uk](http://www.mytube.mymnd.org.uk)

**Patient declines feeding tube**

Consider completing Advance Decision to Refuse Treatment (pack available from MND Association). Inform GP and others.

Ongoing oral intake as appropriate and ongoing support from Dietitian and SALT

**Patient would like to be assessed**

**Respiratory assessment**

Consider Consultant referral to respiratory specialist

FVC<60%

FVC>60%

**Assessment by MDT e.g. Dietitian; Nutrition Nurse Specialist/Practitioner & Consultant Gastroenterologist (Consider who is delivering care)**

**MDT assessment**

Admit to neurology or other acute hospital bed for insertion of appropriate feeding tube

Education of patient/carer by Nutrition Nurse Specialist/Practitioner Dietitian & Nutricia Nurse. Refer to HEN team.

Pt/carer **NOT** willing, confident/competent

**Remain in acute hospital awaiting Package of Care for home/nursing. Transfer to local Palliative Care Hospice**

Pt/carer willing, confident and competent to manage tube/feeding

**Discharge home**

Ensure GP and patient aware that if complications arise to present to ED (NPSA guidelines)

**2-5 working days post procedure**

Review by SALT/dietitian as out-patient/at home/on phone as per NPSA guidelines

**Ongoing care of tube by community staff/Home Enteral Nutrition Team**

Reference: <https://www.nice.org.uk/guidance/ng42/chapter/Recommendations#nutrition-and-gastrostomy>  
<https://www.mndassociation.org/wp-content/uploads/Eating-and-drinking-with-MND-final-web-PDF-2017.pdf>

This pathway has been drawn up with the named service providers involved.

Revised by Dorset MND working party. June 2020. Review June 2022.